

## **Pre-symptomatic Testing**

### **Procedure for Huntington's Disease**

'A guide for patients'

#### **Testing for the Huntington's Disease gene (HD)**

This leaflet explains the protocol for pre-symptomatic testing for Huntington's disease (HD) in South East of Scotland. A pre-symptomatic test predicts whether or not a person, who has a family history of Huntington's disease, will develop the disease themselves. The protocol is usually carried out over a series of appointments.

#### **Introductory appointment**

At the first appointment you will meet with a member of the Clinical Genetics team. You will usually see this person at each appointment.

#### **No testing will be done at this appointment.**

We will ask about your family history of Huntington's disease to ensure that we are testing for the right condition.

We will also discuss

- the symptoms and signs of Huntington's disease
- how it is passed on through families
- what your chances are of inheriting a disease causing Huntington gene
- how the test works and its limitations
- the effect a "good news" or "bad news" result may have on you and your family.

If you still wish to be tested, we will make an appointment for you to begin the formal testing programme. Some people, however, decide that they do not wish to go ahead. You are free to stop at any time during the testing programme.

## Second appointment

This appointment is usually at least one month later.

The aim of this appointment is to look at the advantages and disadvantages of knowing for certain whether or not you are going to develop Huntington's disease. Once we have given you the result you can never go back, so it is important that you are sure that you want to know before we test you.

During the first or second appointment, the clinician may discuss the opportunity of an additional appointment with a psychologist.

## Third appointment

This appointment gives you the chance to talk through any matters which may have arisen since the first appointment.

If, at the end of this appointment, you decide that you want to proceed, then we will take the blood sample. The result is usually available two weeks after the blood sample is taken.

## Result appointment

This appointment is to give you the result of the test in person. We never give out these results over the telephone or in a letter. We would encourage you to bring someone with you who can offer you support. It is your decision whether you want to have the person in the room with you when you receive your result.

A result letter is sent to you following your appointment and this is copied to your GP. The letter will also include details of any follow up arrangements agreed between you and the clinician.

We understand that this process may seem very long. The protocol is the result of much discussion with people who have already been tested and with staff involved in the testing.

**You do not have to convince us to test you. It is your decision whether or not to have the test. We are here to provide information, to help you think through the issues involved and to provide support.**

**Remember that you can withdraw from the programme at any time. The protocol is a guide and if you require more appointments over a longer period of time we would be able to arrange this.**

## Scottish Genetic Centres

**If you need more advice about any aspect of the pre-symptomatic testing procedure for Huntington's disease, you are welcome to contact:**

### **Clinical Genetics Departments**

#### **Northern Scotland**

(main base Aberdeen)

Tel: 01224 552120

(Aberdeenshire, Moray, Highland, Western & Northern Isles)

#### **Tayside**

(main base Dundee)

Tel: 01382 632035

(Perth, Kinross, Angus, North East Fife)

#### **South East Scotland**

(main base Edinburgh)

Tel: 0131 537 1116

(Borders, Lothian, South West Fife)

#### **West of Scotland**

(main base Glasgow)

Tel: 0141 354 9200 / 9201

(Glasgow, Argyll & Bute, Ayrshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

Further information and support is available from:

**Scottish Huntington's Association**

Scottish Huntington's Association, Business First, Linwood Point, PA1 2FB

Phone: 0141 848 0308

Email: [sha-admin@hdscotland.orgf](mailto:sha-admin@hdscotland.orgf)

For more info: [www.hdscotland.org](http://www.hdscotland.org)

Charity Number SC 010985

Version 5: March 2016

Due for review: March 2018

Leaflet no: 018